

Patient Perspective

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I was a trained and published neuroanatomist, teaching and performing research in the Harvard Medical School Department of Psychiatry when an arteriovenous malformation (AVM) ruptured in the left hemisphere of my brain. I was 37 years old and at the top of my game. I did not know that the AVM was there, and, in the course of 4 hours on the morning of the stroke, I could not walk, talk, read, write, or recall any of my life. I did not even know what a mother was, much less, who my mother was. I had become an infant in a woman's body.

Two weeks after the hemorrhage, I underwent a craniotomy, during which a blood clot the size of a golf ball was removed from the temporal region of my left hemisphere. For the 2.5 weeks before the surgery and 2.5 weeks after the surgery, I existed inside a completely silent mind that was totally absent of all language. I was aware of the present moment, but I was no longer capable of tracking thoughts and ideas across time. I experienced a sense of gratitude and euphoria. As my left parietal region was swimming in a pool of blood, and I could not distinguish the boundaries between where I began and where I ended, I viewed myself as a ball of energy that was as big as the universe. Although I could not use any of the skill sets of my left brain, my right brain remained completely functional, and I could easily read the facial and body language of those around me. I could tell if you were comfortable in your skin, or if you wanted to be here with me. I could tell if you were a kind person, or an impatient one.

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It took 8 years for me to completely recover all of the left brain functions that I had lost, and I have outlined this journey in the memoir *My Stroke of Insight*, which spent 17 weeks on the New York Times bestseller list in 2008. The book has been printed in >30 languages and has remained the no. 1 book on stroke in the Amazon marketplace for 10 years.

The concept that the brain is not capable of recovering is old school. Although it is true that we have an enormous capacity to recover circuits and function inside of the first 6 months after trauma, thanks to neuroplasticity and neurogenesis, there is really no end to the ability of our brain to recover over time. Unfortunately, many of the practitioners I speak with still stunt their patients' recoveries by telling them that the brain cannot recover completely—especially after the first 3 or 6 months or, even, 1 year. As a result, patients stop trying. When we treat patients as though they have the ability to recover, they recover more than when we treat them as though they cannot recover. It is important that we use our power in positive ways.

If I could influence change in the world of neurosurgery, I would ask that you inquire about your hospital's policy on taking vitals. We have known for decades that a typical sleep cycle lasts between 90 and 110 minutes. We know from research that even normal healthy people, when deprived of rapid eye movement sleep, will become psychotic within a few days. Insisting that vitals are taken every 60 minutes or encouraging nursing staff to disturb patients when they are sound asleep makes absolutely no sense if we are trying to help them heal. Some hospitals have adopted new policies that are more patient friendly. I cannot stress enough that sleep is critical to the healing process. Simply shifting this policy would allow patients to heal more quickly and more thoroughly.

Also, I would like to emphasize that it does not take any more of your time to be kind, available, and attentive during your rounds. An easy smile, an appropriate touch of a shoulder or gentle squeeze of a foot, a pause and sincere smile or thumbs up before you dart out the door can make all the difference in how safe I feel in your care and how competent I view you, not only as a neurosurgeon, but also as a human being. Any trauma to the brain places us in a state of not feeling completely familiar with

ourselves; thus, your reassurance that you are looking out for us is a true gift. It is so easy to be distracted by the pings, rings, and other people, but in those few moments when you are with me, please be with me.

I learned that there are 2 types of people that patients encounter when we are desperately ill. There are those who bring us energy, cheer us on, and help refuel us, and there are those who take our energy away with their own fear and negativity. The latter people speak loudly to us, they cry around us, they essentially freak out with fear in our presence, and some family members might actually fight among themselves. Others will blast the radio or push the television into our faces, thinking that we need loud stimulation or they might take us in our wheelchairs out into noisy halls. I needed someone to protect my energy from drainage. The television, distraught family members, loud noises, and bright lights all drained my precious energy and made me want to zone out into “LaLa land.” I needed to be surrounded by kind and gentle people and soft lights and permitted to sleep as much as I could. My brain was desperate for quality sleep, and I needed everyone to respect that. I did not need to see my physician more often, but I did need my physician to insist that my sleep was respected, my sensory systems were not overloaded, and fear was left outside my room.

After the publication of my book, I have been contacted by individuals whose loved ones have had a stroke or brain trauma, and I have always encouraged them to immediately stop freaking out. I let them know that it will be weeks, if not a full month, before we really know what is going on with that particular brain, because the trauma-induced swelling can mask the reality of the traumatic situation. Many neurologists and neurosurgeons have been trained to not give false hope, so, instead, they end up taking hope away. I do not think that is fair, and, based on what we now understand about neurogenesis and neuroplasticity, I do not think it is accurate.

I am living proof that the brain can recover from severe trauma, and I am not the only one. I ask that you reevaluate your own beliefs on this subject. Some professionals have praised my recovery, others still refer to me as brain damaged, although I have completely recovered. What were you taught and how long ago? I hope you are open to incorporating patient feedback into your practice, and I hope you will read

My *Stroke* of Insight: A Brain Scientist's Personal Journey. Although it discusses my personal journey, many of my readers have overwhelmingly reported having similar experiences, which I hope will inform your practice. At the back of the book >40 recommendations for recovery have been provided that I hope you will consider.

Thank you for all you do to help your patients' recovery.